

FORM FOR INVESTIGATING SUSPECT OR CONFIRMED CREUTZFELDT--JAKOB DISEASE (CJD)

I. Suspect CJD General Patient Information
General Instructions for the interviewer
1. If more information is available, record on the additional information sheet and attach.
2. CJD incubation can be up to 30 years; try to help interviewee remember as far back as possible.

Patient Name	Last:	First:	Middle:
Date of birth: / / (mm/dd/yyyy)	Sex: Male <input type="checkbox"/> Female <input type="checkbox"/>	Date form filled out: / / (mm/dd/yyyy)	
State of residence:		County of residence:	
Ethnicity	<input type="checkbox"/> Hispanic or Latino	<input type="checkbox"/> Not Hispanic or Latino	
Race (mark one or more)	<input type="checkbox"/> White	<input type="checkbox"/> Black or African American	<input type="checkbox"/> Asian
	<input type="checkbox"/> Native Hawaiian/Other pacific islander	<input type="checkbox"/> American Indian/Alaska Native	<input type="checkbox"/> Unknown
Country/Region of Origin of Forebears			

Patient occupation(s)	Dates
1.	
2.	
3.	

Does/Did the patient have a known history of foreign travel?	Yes/1	No/2	Unknown/9
If yes please list travel locations and dates.			
Travel Location	Dates		
1.			
2.			
3.			
4.			

Suspect CJD Case Hunting/Wild Game Information			
1. Does/Did the patient have a known history of hunting or eating wild game?	Yes/1	No/2	Unknown/9
2. If yes please complete the following.			
Type of game	State(s) of harvested game	Year(s) of activity	
3. Did patient field dress carcasses?	Yes/1	No/2	Unknown/9
4. Does/Did the patient consume wild game muscle tissue?	Yes/1	No/2	Unknown/9
5. Does/Did the patient consume brain or organ meats?	Yes/1	No/2	Unknown/9
6. If yes to #4 or #5, please complete the following			
Frequency of consumption	Type of meat consumed		

Suspect CJD Case National Prion Disease Pathology Surveillance Center (NPDPSC) Information			
1. Has the NPDPSC been contacted regarding this case?	Yes/1	No/2	Unknown/9
2. Date of NPDPSC contact: / / (mm/dd/yyyy) Contacted by: _____		Tel: 216-368-0587 Email: cjdsurv@cwru.edu	
Note: The NPDPSC will pay for autopsy expenses if they are contacted ahead of time and will help make the arrangements. It is important to submit the required paperwork before the patient passes away when possible.			
3. Has the NPDPSC paperwork been submitted to the family for consent?	Yes/1	No/2	Unknown/9
4. Date NPDPSC paperwork submitted to the family / / (mm/dd/yyyy)			
• Brain Only Autopsy Informed Consent Form	Yes/1	No/2	Unknown/9
• Patient Information Form	Yes/1	No/2	Unknown/9
• Contact Information	Yes/1	No/2	Unknown/9
5. Has the NPDPSC paperwork been submitted to the NPDPSC?	Yes/1	No/2	Unknown/9
6. Date NPDPSC paperwork submitted to the NPDPSC / / (mm/dd/yyyy)			

II. Suspect CJD Case Clinical Data				
Date of initial symptoms: / / (mm/yyyy)	Does the patient have a family history of CJD or early onset dementia?	Yes/1	No/2	Unknown/9
If yes please comment:				

1. Does / Did the patient have Rapidly Progressive Dementia?	Yes/1	No/2	Unknown/9
Definition: A dementia illness in which the time course from first symptom to dementia is less than two years, and often less than one year.			

2. Does / Did the patient have early psychiatric symptom(s)?	Yes/1	No/2	Unknown/9	
Definition: Early psychiatric symptoms may include anxiety, apathy, delusions, depression, and/or withdrawal.				
If yes please complete the following:				
Symptom	Symptom Onset Date	Did the patient see a doctor?	Attending physician	Contact Information
• Anxiety		Yes/1 No/2 Unknown/9		
• Apathy		Yes/1 No/2 Unknown/9		
• Delusions		Yes/1 No/2 Unknown/9		
• Depression		Yes/1 No/2 Unknown/9		
• Withdrawal		Yes/1 No/2 Unknown/9		

3. Does / Did the patient have persistent painful sensory symptom(s)	Yes/1	No/2	Unknown/9
Definition: Persistent painful sensory symptoms refer to abnormal or disagreeable sensation produced by ordinary stimuli.			

4. Does / Did the patient have dementia?	Yes/1	No/2	Unknown/9
Definition: Dementia refers to disorientation and/or impaired memory, judgment and intellect.			

5. Does / Did the patient have poor coordination/ataxia?	Yes/1	No/2	Unknown/9
Definition: Ataxia is the inability to coordinate muscle activity, causing jerkiness, lack of coordination, and inefficient voluntary movement.			

6. Does / Did the patient have myoclonus?	Yes/1	No/2	Unknown/9
Definition: Myoclonus constitutes shock-like contractions of a group of muscles.			
7. Does / Did the patient have chorea?	Yes/1	No/2	Unknown/9
Definition: Chorea is irregular, spasmodic, involuntary movements of the limbs or facial muscles.			
8. Does / Did the patient have dystonia?	Yes/1	No/2	Unknown/9
Definition: Dystonia are involuntary muscle contractions that force certain parts of the body into abnormal, sometimes painful movements or postures.			
9. Does / Did the patient have hyperreflexia?	Yes/1	No/2	Unknown/9
Definition: Hyperreflexia constitutes an abnormal increased action of the reflexes.			
10. Does / Did the patient have visual disturbances?	Yes/1	No/2	Unknown/9
Definition: Visual disturbances may include the following:			
a. Visual field cuts refer to blindness in one half of the visual field.	Yes/1	No/2	Unknown/9
b. Cortical blindness is when the visual cortex of the brain is not working. The patient is blind and the eyes are anatomically and structurally intact.	Yes/1	No/2	Unknown/9
c. Visual agnosia is when the patient cannot recognize familiar objects.	Yes/1	No/2	Unknown/9
11. In addition to dementia, does/did the patient develop at least two of the following five neurological signs at least four months after illness onset: poor coordination, myoclonus, chorea, hyperreflexia, or visual disturbances?	Yes/1	No/2	Unknown/9
Specify/comment:			
12. Overall, was the duration of illness longer than 6 months?	Yes/1	No/2	Unknown/9
Specify/comment:			
13. At any time, has the patient received human pituitary growth hormone, a dura mater graft, or a corneal graft?	Yes/1	No/2	Unknown/9
If yes, please specify:	Procedure(s)		
	Where		
	Date(s)		

III. Attending Physician Information:			
General Instructions for the interviewer			
1. If more information is available, record on the additional information sheet and attach.			
2. Please list all physicians who have cared for the patient at any time during the patient's illness, as well as any procedures/tests performed, and at what facility/hospital.			
3. Please specify which facility/hospital regardless of inpatient or outpatient status.			
Hospital	Date(s)	Attending Physician(s)	Procedure(s) performed/reason hospitalized
		Name: Position:	
		Name: Position:	
		Name: Position:	
		Name: Position:	
		Name: Position:	

IV. Information on Procedures Performed Related to/During Patient's Illness:			
General Instructions for the interviewer			
1. Please attach medical reports if available.			
1. Was a Magnetic Resonance Imaging (MRI) procedure performed?	Yes/1	No/2	Unknown/9
Assessment/results:			
2. Was an Electroencephalogram (EEG) procedure performed?	Yes/1	No/2	Unknown/9
Assessment/results:			
3. Was a lumbar puncture (spinal tap) 14-3-3 performed?	Yes/1	No/2	Unknown/9
Assessment/results:			
4. Was a brain biopsy performed?	Yes/1	No/2	Unknown/9
Assessment/results:			
5. Was genetic testing for prion protein gene mutation performed?	Yes/1	No/2	Unknown/9
Assessment/results:			
6. Were test sample(s) from section IV sent to the NPDPS?	Yes/1	No/2	Unknown/9
If yes, please specify which sample(s) were sent:			
Assessment/results:			
7. Did routine investigation of the patient indicate an alternative, non-CJD diagnosis as the etiology for the patient's symptoms?	Yes/1	No/2	Unknown/9
Assessment/results:			

V. Post-Death Assessment Data:			
Date of death __/__/____ (mm/dd/yyyy)		Age at death: __ __ years	
1. Was an autopsy performed by a neurosurgeon recommended by the NPDPS?	Yes/1	No/2	Unknown/9
Specify/comment:			
2. Hospital where autopsy was performed	Hospital Address	Date of Autopsy	Autopsy Physician
	Address:		Name:
	Phone #		Phone#
Autopsy results			
Assesment/Results			

3. Were autopsy samples sent to the NPDPS?		Yes/1	No/2	Unknown/9
If yes, date samples sent to NPDPS		Date samples received at NPDPS		

NPDPS test results
General Instructions for the interviewer
1. Please attach neuropathology reports if available.
Aminohistochemistry:
Western Blot:
DNA Genetic:

Additional Information for Investigating Suspect or Confirmed Creutzfeldt--Jakob Disease (CJD)